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To quantify experience? Methodological issues in the behavioural/psychological treatment of complex partial seizures

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This paper will attempt to identify some of the major methodological hurdles that are present when treating or researching seizure conditions using neurobehavioural approaches. An overview of the unique methodological problems that arise with behavioural/psychological treatments will be discussed. The author will focus on personal experiences with complex and simple partial seizures, looking into some methodological questions that arose after his seizure activity was reduced using a behavioural technique. Several main issues will be examined as they may apply to seizure and personality type, and how they can influence treatment and results. Finally, possible directions toward improving methodology will be suggested.

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Key words: behavioural and psychological treatment; simple partial; complex partial; methodology; limitations.

INTRODUCTION AND BACKGROUND

The author is a 32-year-old male who has had a seizure disorder for the majority of his life. A formal diagnosis was made and confirmed with EEGs at age 12, when he had his first generalized tonic–clonic seizure (GTCS). He began doing research on his seizure activity in 1989 when, after nearly 4 years of seizure and antiepileptic drug (AED)-free life, he began having a large number of simple partial (SP) and complex partial (CP) seizures. Similar episodes occurred between the ages of 5 and 7, but there had been no activity of this type for over 15 years. On average, between three and seven episodes would occur per day, with a range of 0–15. Duration would range from about 1 second, up to 2 minutes.

The unique thing about these episodes was that they were almost exclusively experiential in nature, with only minimal physiological manifestations. When they did occur, the only outwardly visible sign might be a flush or sweat response, and perhaps a confused or uncertain expression on the person's face. There were discrete sensory aspects to the episodes, including micropsia, or 'Lilliputian vision' and 'macrotactility', in which the sense of touch would become altered in such a way that the hands, feet and sometimes head would be perceived as vastly larger than normal. This distorted mode of experience was restricted to tactile sensations in the extremities, and there were no corresponding visual confirmations of these unusual sensations. Less common were olfactory/gustatory hallucinations, in which a nonspecific but slightly sickening or burning smell, similar to sulphur, would be experienced. Often a corresponding taste would be encountered at the same time. On rare occasions a very minor diffuse and unformed auditory experience would be present.

In addition to purely sensory feelings, other experiences would manifest themselves during the episodes. There were psychic phenomena, including feelings of mental telepathy, *déjà vu*, autoscopic phenomena, and the like. Mental imagery, consisting primarily of stored memories from similar seizures that occurred during childhood, and which manifested as a 'flashback' type of experience, was also present. On days of heavy activity, the author's entire perception and awareness was described as being 'skewed', in that his experience felt slightly distorted or 'off-centre'.

As the seizures continued to occur, the author began to take closer notice of them, and described what he called the general 'cycle', or course of experiences he underwent during an episode. A specific triggering mechanism was never isolated. First, there would be a spontaneous burst or spike of energy that would sud-

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denly appear in his consciousness. It would be experienced as a short, intense flash of energy that would make itself known throughout most or all sensory faculties. This signalled the beginning of a seizure. The next stage was labelled the 'ascension' or 'building' stage. After the burst, the person would feel a gradual build-up of 'experiential energy', vaguely localized in the abdominal area. It was often felt as a 'vortex' of energy, rotating in an anticlockwise direction, which would continue to increase. After a given time (which varied considerably), the energy build-up would reach what was described as a 'zenith', or 'critical mass'. At this point it would be 'released', whereupon a vertical exodus of the energy would be experienced, originating in the abdominal area and rising up and out of the head very quickly. A profuse flushing and sweat response would follow, as the perception of hot energy passed through him. After the 'release', there seemed to be an 'after-effect' of the experience, in that it would 'echo' or reverberate through his consciousness for up to a minute or more, finally dissolving and fading. There was considerable variance in the intensity, duration, and imagery associated with the respective 'stages', and not every experiential seizure was of this kind.

DEVELOPMENT OF THEORY AND TREATMENT PROCEDURE

Whenever the author would have a seizure, a written account of the experience would be recorded and then analysed for the light it could cast on the cognitive structures associated with the seizures. As analysis continued, the evidence began to suggest that specific beliefs and meanings were attached to and linked with the experiential seizures. The hypothesis that emerged posited that if such was indeed the case, then altering those same specific or general beliefs and meanings may, in turn, alter the experiences and quite possibly the seizures themselves. Based on this, a treatment approach was developed and implemented using behavioural methods, the goal of which was to exert some type of conscious, reconstructive influence over the seizures.

The implementation of this treatment was undertaken from two perspectives. The first was labelled the 'primal' level. This component sought to address the largely subconscious, automatic responses associated with the seizures and seizure experiences. Whenever a seizure would occur, as soon as there was awareness of it a very elementary assertion was firmly recited both mentally and often verbally. This would be repeated as many times as possible while the seizure experience persisted. It was intended to exert influence on the deeper and most fundamental levels of the mind, requiring a corresponding level of communication. The primary goal of this component of the procedure was to change the basic semantics and emotional affinities connected with the seizure activity from a decidedly negative to a decidedly positive, or integrative orientation.

The second element to this approach was what was called the 'formal', or cognitively structured level. After an inventory of semantics associated with the seizure activity had been established, the author began a combined and interactive process of research and introspection. Several fields of medicine, psychology, and philosophy were examined for their interpretations of phenomena like his seizures. As this continued, a written subjective report, reflection, and analysis of the activity continued, and was used as a reference for the author's own feelings and beliefs about the activity. A synthesis of these two bodies of knowledge was then performed and the new set of seizure-related beliefs and associations created.

After the new semantics and beliefs had been created, it was then necessary that they (1) become part of the person's consciousness, and (2) become linked with the seizure activity. The primal therapy served both ends at its levels of awareness. It was engaged only when a seizure would occur, and hence it entered the primitive levels of consciousness and was directly and immediately associated with its desired link. In the higher levels of consciousness, the formal writing of the theory and its components accomplished the first task. The second task required a period of active reinforcement and processing of the new associations by the mind. It is here where a bridge between the formal and primal levels of treatment (and seizure experience) had to be constructed, eventually allowing each to provide feedback to the other, and to reinforce each other in doing so. It is this end that would establish control of the condition. Once these treatment procedures were initiated, they continued to be repeated whenever a seizure would occur, as well as in the author's writings on the subject.

RESULTS

Over a period of about 12 months, the frequency of SP/CP seizure activity was significantly reduced. The author's current seizure frequency averages from 0 to 2 SP/CP episodes per month. Further, the seizure experiences have changed from being fear-filled and negative, to decidedly neutral and even *positive*. In fact, there were some seizure episodes that were reported as enjoyable. The experiential content of some of the seizures could be altered as they were occurring, and others even stopped in mid-ictus. The mid-ictal modifications and arrests occurred in the latter stages of the

treatment procedure, and continue today. Through research and analysis of his seizure activity (not to mention the significance of personally experiencing several hundred of these seizures), the author was often able, once a seizure would begin, to quickly recognize what type it was going to be. This set of data was developed in the early stages of the procedure, before any active efforts to influence the seizure activity were undertaken, and was used as the reference for tracking changes in the seizures as they occurred. During the latter stages of the treatment period, when a seizure would occur, instead of passively allowing the episode to continue, an immediate effort was attempted to exert controlling influence over the seizure. Modifications of the seizures consisted of changes in the characteristics or duration of the individual experiential components of a seizure, but which did not alter the overall 'cycle' of the episode. For example, the individual would be in the midst of a seizure, and then consciously focus on an external object or an internal image or thought. Once this was initiated, the given object or thought would then become (to varying degrees) a component of the seizure experience. A mid-ictal arrest, on the other hand, involved an active interruption of an ongoing seizure cycle. These types of seizure experiences were very strong, and stood out in stark contrast to non-controlled or modified episodes. They were characterized by a disruption of the series of experiential events, occurring at whatever point in the seizure that the arrest effort was initiated. Immediately after the arrest/control effort, the seizure experience would suddenly change, and become one of a brief period of dizziness or light-headedness, followed by a fairly steep reduction and fading of its energy and presence in consciousness. The experience was as if an opposing force had struck the propagating seizure, reducing its available energy below the threshold at which it could continue[1].

The seizures' durations and related temporal aspects seem to have also been influenced by the procedures. The duration of the seizures that were arrested was definitely shorter than those that were not actively subjected to any type of controlling efforts. Further, as the behavioural training continued and was applied to more and more seizure episodes, the author became more and more conscious of the seizure signs and activity. The temporal experiential aspects of the seizures have been significantly changed, in that an oncoming seizure can now be recognized much earlier in its propagation than was the case before the treatment process began. The author can now recognize that he is going to have a seizure up to several minutes before it actually occurs, whereas before they would strike with little or no conscious warning, and the term 'seizure' was all too appropriate a term. These changes allowed him to be able to initiate controlling influence at earlier and earlier points in the seizure 'cycle'. Reducing the duration, in this sense, was a function of initiating a conscious effort to stop the seizure and, depending on the point during the seizure at which that effort was exerted, the seizure might be longer or shorter.

Perhaps one of the most unique results of this treatment procedure is an experiential element that has become a part of nearly every CP/SP seizure experience that now occurs. As the seizure is occurring, it is reported now that there are always what can only be described as a series of experiential 'inflection points' where the individual intuitively *knows* that if he wants to, he can *immediately* stop the seizure, or just let it continue on. It is reported thus: 'I will be "going along" with the seizure, experiencing it and "watching it from a distance" (making mental notes of the seizure's elements) at the same time, and a strong image/thought suddenly comes into my consciousness that says: "What do you want to do with this one? Stop, or keep going?"' It is described as very fundamental 'if–then–else' logic. Depending on what he wants to do, he may say to himself: 'No! I want to stop this! Now!' At that point, the individual will go through an experience similar to the 'mid-ictal arrest' process described above, and the seizure immediately fades. If there is a conscious decision to *not* arrest the seizure, and instead let it proceed however it might, the person will say to himself, 'Let's go on for a while'. In this instance, the seizure will continue on for a bit until another 'inflection point' is reached, where another opportunity to stop or continue will arise. Depending on the overall duration of the seizure, there may be one to three of these experiential 'inflection points' over the entire episode. They are now very common elements in the seizures, whereas they were *never* there before. It has also been reported that the ability to control or arrest the seizures is not restricted to these points in the seizure cycle. They seem to be some type of semantic icons that have been successfully associated and integrated with the seizures, and which now appear during the episodes. Sometimes the individual just 'rides along', and lets the seizure go wherever it wants to, or other times he will immediately try to stop it. Regardless, there seems to be a conscious ability to take either path.

TREATMENT RAISED SOME INTERESTING QUESTIONS

Even though this case reported some success controlling seizure activity using behavioural and psychological means, an issue that is still not resolved in any final sense is exactly what the mechanism was that changed the seizure experiences, and how reconstructive influence over their content was able to be exerted. As was

related in a previous article:

> Were there changes in the cognitive structures associated with the seizure episodes, which literally exerted some type of physio-chemical change on the brain, altering the seizures' chemoelectric pattern (and hence the experiences) in a purposeful way? Or, were there physio-chemical changes that occurred first, and which were manifested as psychological shifts and changed experiences? Further, could the physiological seizure activity have remained constant, and the cognitive transformations provided a different interpretation of the same energy patterns, resulting in a new and altered experience? Muddying the already cloudy waters even more so, were the changes brought about through some combination of two or more of the above, or even by some as-yet unknown process? Is it possible to make this determination? If so, how?[1].

Given the way that the seizures/experiences were changing, two questions arose:

- Could the same type of seizure be consciously interpreted in different ways?
- Is it possible for different seizures to be felt as identical experiences?

To illustrate, suppose that EEG traces as well as verbal descriptions of two independent seizures from an undisputedly diagnosed patient could be recorded. If the EEG readouts of both seizures were identical (within statistical tolerances, and with all other methodological issues held constant), and the patient's description of each of the seizure experiences were completely different, what would the best explanation be? Alternatively, if the EEG readout of each seizure was significantly different (in statistical and diagnostic terms), yet the patient described no difference in either of the seizure experiences, what would be the diagnostic answer here?

In these hypothetical cases, as well as in the author's case, the diagnostic lines become blurred, and the question becomes one of:

- What is the 'seizure'?
- What is the 'experience of the seizure'?

How can one definitively differentiate between the two? Where does *'spontaneous chemoelectric discharge localized in the medial temporal lobe'* give way to *'a sudden detailed, specific memory from childhood accompanied by altered visual and tactile sensations'*?

In isolation, this does not necessarily present a significant diagnostic challenge. If the seizures' experiential components remain constant, then the above scenario might easily be explained in terms of localized seizures that trigger a specific memory or sensation. These cases, while not common, have certainly been documented. However, what confounded this otherwise reasonable explanation in the present case was the way the seizure experiences changed. The experiential transformations first occurred spontaneously, and then the changes were able to be actively influenced. What mechanism or hypothesis could explain this? What would a neurologist's conclusion be? What would a psychologist's conclusion be? In isolation, each would most likely follow the well-known path and discount the other elements. This was the case when a professional in each discipline was consulted about the condition. While understandable, neither interpretation in itself is sufficient to fully explain the activity. A confirmed diagnosis of epilepsy was present, which supported a neurological component, and the seizures were cognitive/experiential in nature, with a dynamic quality to them, which presented a psychological component. To focus on one or the other as the single, ultimate cause is to paint an incomplete picture of the condition, and ignore critical components of it.

UNLESS YOU QUANTIFY, IT DOES NOT QUALIFY

A crucial question regarding this case is the quantifiability of what was done. If it cannot be quantified, then what kind of validity does it have in the scientific sphere? From the patient's own perspective of the seizure experiences, it may be said that the treatment was indeed effective. Further, given the nature of the activity, it may be arguably asserted that it was indeed 'quantified' in one of the few ways possible, through self-reports. However, this type of data is entirely subjective, which justifiably raises questions of validity and reliability.

If the patient had been connected to an EEG for several weeks during periods of heavy seizure activity, some type of empirical evidence may well have been gleaned. Unfortunately, it was not possible to gather such data in this case. However, the utility of EEG traces may have limitations when it comes to experiential seizures. The EEG evidence could have provided further validation of the seizure disorder, lowering the probability that the activity was not truly epileptic in nature. This, in fact, was confirmed by a surface EEG that was performed during the latter stages of the treatment period. It may also have provided seizure localization data and some qualitative

insight as to the physio-chemical nature of the disorder, but what about the experiential and cognitive components? How does chemo-electric neurological activity ('normal' and 'abnormal'), as expressed in EEG traces, get translated into discrete cognitive experiences? EEG diagnostics simply do not have such advanced capabilities. Recordings taken before, during, and after treatment may well have been able to provide some insight into whether or not and/or how the seizure activity changed as a result of the behavioural treatments. However, even if such data were available, it is doubtful that it would provide all of the answers, and the question would still remain as to how it actually happened.

You must qualify before you can quantify

Research on the mind/brain and the two (or one) interacting currently has limits on how much we can subject it to reliable, valid empirical analysis. A robust research model is very important, but the nature of this type of research involves some very significant 'unknowns'. Some would even go so far as to call them 'unknowables'. If you cannot define or qualify something, then quantifying it presents an even greater challenge. Until these enigmatic gaps begin to be filled, they must be acknowledged and accepted as part of the challenge of this type of research.

WHAT ABOUT THE POPULATION OF PEOPLE WITH EPILEPSY OVERALL?

Admittedly, what the author specifically did with his seizures may not be directly generalizable to the population of people with epilepsy at large. The seizure type was somewhat unique, seizure frequency was high, and the experiential elements were certainly not the norm. It is also believed that the author's background and years of personal experience with seizure activity both contributed to the development and implementation of the treatment approach. If such a confluence of factors is a requirement for success, then achieving it on a widespread level may not be so easy. There are several main areas that could cause methodological problems with behavioural research and treatment:

- Problems with different seizure types.
- Personality and psychological profile of patient.
- AED issues.

Problems with different seizure types

One of the most critical issues in treating seizures with behavioural approaches is what may be called the 'seizure profile'. This is primarily a clinical evaluation, and involves the type(s) of seizure the patient is subject to, their frequency, severity, and so on. This particular case involved a significantly large number of SPs and CPs, occurring without any other type of seizure, and which primarily manifested in the author's ongoing conscious awareness. Because of this, a tangible, accessible object associated with the seizures was created in the mind, which could then have structured behavioural action directed at it with relative ease. Also, because of the high seizure frequency, this object was consistently reinforced, which further increased its presence in the mind.

This may or may not be so simple for those with other types of seizures. Depending on the seizure profile, behavioural treatment efforts may have varying degrees of success. Patients whose seizure profile consists primarily of GTCSs, absence seizures, or other 'non-experiential' seizures could possibly have a more difficult time creating the 'seizure object' in their minds that would allow behavioural treatment to be significantly effective. These types of episodes may not have a recognizable experiential component, and often involve a *loss* of ongoing conscious awareness rather than an alteration of it. Hence, they do not immediately present themselves to the mind of the person who has them as vividly and concretely as SPs and CPs might.

Further, there may be patients whose seizure type may be very amenable to behavioural treatment, but whose seizure frequency is relatively low. From the author's personal experience, an integral element of effective behavioural treatment of epilepsy involves creating and directing feedback and reinforcement processes at the seizures. While a small part of this can be done 'offline' (in the interims between seizures), it is felt that the optimal opportunity to apply a behavioural tool is during an actual seizure. This, of course, requires a significant amount of seizure instances in order to be effective. If they are infrequent or rare, the analysis, feedback, and restructuring of the cognitive structures associated with the seizures can be significantly slowed down. Also, if a cognitive association is not reinforced with some regularity, it eventually becomes extinct. Behavioural restructuring of the seizure activity may not even be possible because of the simple lack of opportunities for doing so caused by the low seizure frequency.

While the two issues discussed above may present challenges to many patients and clinicians who undertake behavioural treatment, it should be remembered that such is the case with all types of treatment, in-

cluding pharmacological methods. The diversity of diagnoses, treatments, and responses to pharmacological treatments illustrate that much still remains to be learned and refined. The same will be true with behavioural treatment. There will undoubtedly be many patients whose 'seizure profile' does not fit that which allowed the author's treatment to be effective, but who nevertheless have found or will find a way to take control of their activity.

Personality and psychological profile of patient

Clinical data on a patient's seizures is one thing. Psychological data on the personality of the patient, including how they view themselves, their seizures, and how the latter fits in (or not) to the former is not always readily available, and is not traditionally a part of clinical treatment for seizure disorders. A component of behavioural/psychological seizure treatment that is just as important as the seizure profile is the personality/cognitive profile of the patient.

Why is this important?

Given that the primary element of 'self-control' is the 'self', it is important for someone who wants to undertake behavioural/psychological treatment for seizures to be psychologically capable of assuming the responsibility for their part in the treatment process. The author's personal experience with this type of activity leads him to conclude that achieving self-control over seizures requires certain psychological and emotional capabilities. One of the most important, it is believed, is a sense of stability or established groundedness with regard to one's personality or self. A strong and firmly grounded sense of self is the foundation upon which the entire treatment process is built, and if there are neuroses or other psychological problems (whether or not they directly pertain to the seizure condition), these *must* be worked out before behavioural treatment of the actual seizure condition begins. This presents a requirement for a psychological evaluation that should be equal in depth to that of the clinical. This evaluation can be self-directed (as the author's was), or performed by an appropriately qualified therapist. This element is necessary for two reasons.

Eliminating extraneous factors. First, it is necessary to do as much as possible to eliminate or at least minimize any extraneous or confounding factors that personality problems might present. Any number of neuroses or other psychological issues could influence the treatment process, both from the standpoint of designing an effective model, as well as the patient's motivation for, implementation of, and success with the treatment. Psychological problems may or may not be directly attributable to the seizures, and it is important to differentiate the two. A clearly definable, dichotomous case will rarely appear. Seizure-related psychological problems will undoubtedly influence non-seizure-related problems, and vice versa. Where possible, efforts should be made to identify this interaction to increase therapeutic efficacy. Identifying and eliminating these issues will serve to increase the probability that the treatment approach design is directed at the seizure disorder, and *not* an extraneous psychological condition unrelated to the seizures.

Develop referential basis for behavioural tools. Second, the behavioural tools that the author implemented on his seizure activity were developed using a set of beliefs and ideas about the seizures. These seizure-specific beliefs were drawn from his overall belief system and definition of 'self'. As stated above, when the author's seizure research first began, a combined process of research (medical and philosophical) and introspection was begun, to first develop a clearer philosophical and personal perspective. That perspective was then adapted and applied to the seizure activity. The set of behavioural tools that was designed incorporated these sets of meanings and beliefs, as it was felt that the CP/SP seizure activity could best be influenced this way. Hence, if patients go through a personal and psychological evaluation of themselves, the set of behavioural tools that will be made available and mobilized in a treatment procedure will be much stronger and much more effective in controlling their seizures.

One size does not fit all

Although the author did a lot of outside research during the course of his self-treatment, the final set of beliefs and meanings that were developed were *his* and his alone. If another person tried to treat himself or herself using only his data as a reference, it is not believed that they would be as successful as if they approached it from a personal perspective. Personal philosophies and outlooks, it is felt, provide the strongest and most concrete source of motivation for a person. However, these can be vastly different between individuals and cultures, and what may hold significance and motivation for one person may not do so for another. In order for behavioural/psychological treatment to be effective, it is important for the patient to:

(1) understand and have a firm grasp on their sense of self and belief system; and

(2) be able to mobilize and incorporate those beliefs into a constructive approach to influencing their seizure activity.

The best tools a person can use for behavioural treatment are those that are already in place within their mind, and integrating a person's pre-existing belief system into the seizure treatment approach would be the most efficient way to achieve some degree of success. Why? In the author's experience, the person who has seizures (regardless of the type) will spontaneously try to make *some* sense out of the activity. They *must* attach some meaning to and integrate their seizures into their life somehow. Designing and implementing an integrative set of representations will not only increase the probability of seizure control, but also allow the person to begin to reconcile the seizure-related issues within themselves. However, this approach might be much more difficult for some than others, and depending on the results of the psychological evaluation, a more effective approach might be to design and implement a generalized, standard set of tools for the patient to work with.

Potential problems

- How much individual tailoring or modification of treatment will be required in order for the treatment to be effective? How should this factor be integrated into an effective research model, especially as it pertains to measuring effectiveness across patients?
- When research is being considered, how do you have a 'control group' for a particular personality or personality type? Further, can this control group be standardized across patients with different seizure types as well?
- In order for behavioural tools to be effective, it was stated above that a 'significant' amount of seizure instances are required. Establishing standardized parameters for what is considered 'significant' may not be easy, and may vary widely as a function of seizure type, personality type, age, and so on.

AED issues

Another obvious problem with treating seizures with behavioural methods involves AEDs. AED therapy is effective for many patients, but not all. AEDs are also accompanied by a wide variety and degree of side effects, many of them cognitive in nature. Whether or not a patient is on AED therapy could possibly have significant influence on any behavioural treatment and/or research results. There are also ethical issues with regard to AEDs that cannot be ignored when considering behavioural treatments. Several AED-specific issues include:

- Should behavioural candidates be chosen who are or are not on AEDs?
- For patients who undergo behavioural treatment and are concurrently on AEDs, what is the best way to determine if the behavioural treatment results were valid, or attributable to the AED therapy?
- Conversely, can AEDs and side effects mask and/or inhibit the patient's ability to effectively implement and/or benefit from behavioural/psychological methods?
- Many patients who are on AED therapy suffer from or are afraid of the long- and short-term side effects, and are very much interested in alternatives. How should a treatment approach best address reducing/ceasing AED treatment?
- Would the behavioural treatments reveal any differences between AED-controlled patients and AED-refractory patients? How should this complex issue be best approached from a research design perspective?
- How should the issue of a control group be handled for each of the above cases?

When the author did his research on himself, he was not taking any medication of any kind, for any condition. Things may or may not have turned out differently had he been on AED therapy. This case is an exception rather than the rule, and if any significant progress is to be made, then AED issues must be integrated into any research or treatment model.

ADDITIONAL ISSUES

Measuring the success of behavioural research/treatment may seem at first to be quite simple. However, the number and nature of the variables under consideration in these cases can present very difficult problems with regard to research design and interpretation of results. In addition to the methodological issues discussed above, there are other areas that may hold potential for improving the success with these techniques.

Doctor/patient relationship

A cornerstone of behavioural and psychological treatment involves the patients themselves taking a much more active part in the treatment. In the end, it is the patient who will achieve the control over their

seizures. Crucial to success is a personal conviction and belief that they *can* control their activity themselves. The roles of the doctor and the patient, in this context, take on a slightly different character. Instead of the clinician issuing directives to the passive patient, more of the burden of responsibility (psychological and genuine) is shifted to the patient. That is not to say that the clinician's part is in any way diminished. A supportive, motivating physician who actively embraces and encourages this type of treatment can enable a patient to develop an immense amount of confidence in their abilities. This type of relationship would allow the two to work even more closely and effectively toward the common goal of improving this enigmatic condition.

Fundamental issue of 'control'

Perhaps the author's biggest source of fear and stress with regard to his seizures was the ever-present shadow that the condition cast over him. The seizures felt like the proverbial 'Sword of Damocles' hanging over his head, and he was always waiting for the next one to strike. When would the next one happen? What would it be like? Would it be a GTCS? A day did not (and, although to a much lesser extent, still does not) go by without these questions weighing heavily on his mind.

From the author's research, as well as discussions with other people with epilepsy, this element seems to be present no matter what type of seizure a person has. The very term, 'seizure', implies something unknown that strikes without warning from outside oneself, and over which the person subject to it has no control. Feelings of a lack of control can lead to many other psychological/emotional issues, including stress/anxiety, depression and the like, and these conditions do have a physiological component. In some patients, addressing the feelings of lack of control could have a positive effect on seizure frequency. Improving the sense of control could reduce the stress and depression (as well as their accompanying physiological components) specifically associated with the seizures, which, in turn, could reduce seizure frequency. Positive feedback gains could be realized by the patient and reapplied to further the treatment, and so on.

CONCLUSIONS

While behavioural and related medical treatments have existed in various forms for a long time, pharmacological methods of treatment have become the foundation of modern medicine and overshadowed them. However, in epileptology, as in many fields of medicine, more and more researchers and clinicians are (re)acknowledging that psychological, emotional, and other traditionally 'non-organic' factors can influence organic medical conditions. The placebo effect, a documented and widely accepted (but poorly understood) phenomenon, is but a small example of this mechanism. Conditions that were once only thought to be treatable by pharmacological means are now being re-examined under this light, and progress is being made on many fronts.

However, the sheer number of clinical factors presents a considerable challenge to researchers, and the human/psychological factors (which are harder to quantify relative to clinical data) are even more difficult to integrate into a reliable research model. Each of the issues discussed herein cannot be considered in isolation. While each is very important in its own right, they can all have significant effects on other factors. Further, each individual case is in many ways unique, and the key to successful treatment in one patient may be an insurmountable obstacle in another. If these problems were not complicated enough, a patient's seizure activity and psychological stability can often change drastically over time, which creates a moving target of treatment. Identifying key factors that promote or inhibit effective behavioural treatment will require complex analysis and a large set of longitudinal research data. However, as research continues, a coherent body of knowledge should begin to emerge, which will hopefully illustrate underlying common elements in individual cases, continue to refine the methodology, and allow more and more patients to benefit from this remarkable and exciting phenomenon.

REFERENCES

1. Benak, J. Cognitive restructuring of experiential seizures. *Self-Control in Epilepsy* 1996; **7**: 20–32.